



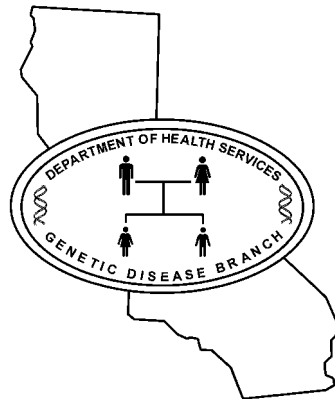
What you should know when your Expanded AFP blood test result is

**Screen Positive: Indicating an increased risk
for Down syndrome**

POSITIVE: DS

THE CALIFORNIA EXPANDED AFP SCREENING PROGRAM

the cal ifornia expanded afp screening program
the cal ifornia depart ment of heal th services, genetic disease branch
850 marina bay parkway, f175, richmond, ca 94804
866-718-7915 (tol l free)



As part of your prenatal care you had the Expanded AFP blood test. This screening test estimates the risk (chance) that you may be carrying a fetus with certain birth defects, such as Down syndrome, neural tube defects, abdominal wall defects and trisomy 18.

The blood test measured three substances in your blood: AFP (alpha-fetoprotein), HCG (human chorionic gonadotropin) and UE (unconjugated estriol). All of these substances are normally found in a woman's blood when she is pregnant. The amounts of these substances change as the fetus grows.

Your test result was "screen positive", indicating an increased risk for Down syndrome. This risk is based on your age and the amounts of AFP, HCG and UE in your blood.

What could have caused your “screen positive” result?

Most of the time, the reason for this result is **NOT** a birth defect. The most common reasons for a “screen positive” result are:

- you are not as far along in your pregnancy as thought, *or*
- the amount of AFP, HCG and UE varied more than usual, without any known pregnancy problem.

To help determine *why your result was “screen positive”*, you will be offered diagnostic follow-up services at a State-approved Prenatal Diagnosis Center. There is no additional charge for approved services.

What can diagnostic tests show?

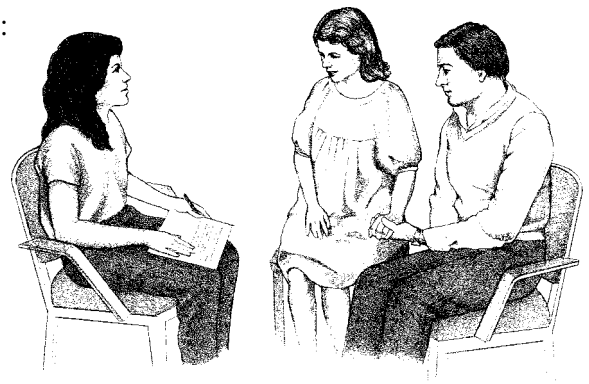
Diagnostic tests can show whether your blood test result was positive because of a change in the due date or because of a problem with the pregnancy. In addition, certain birth defects can be found by examining the chromosomes of the fetus (unborn baby). Chromosomes are packages of genetic information found in every cell of the body. Birth defects can occur when the fetus has too few or too many chromosomes, or when there is a defective chromosome.

Most women with “screen positive” results will have normal follow-up tests and healthy babies.

What are the follow-up services at a State-approved Prenatal Diagnosis Center?

These follow-up services include:

- genetic counseling
- ultrasound
- amniocentesis



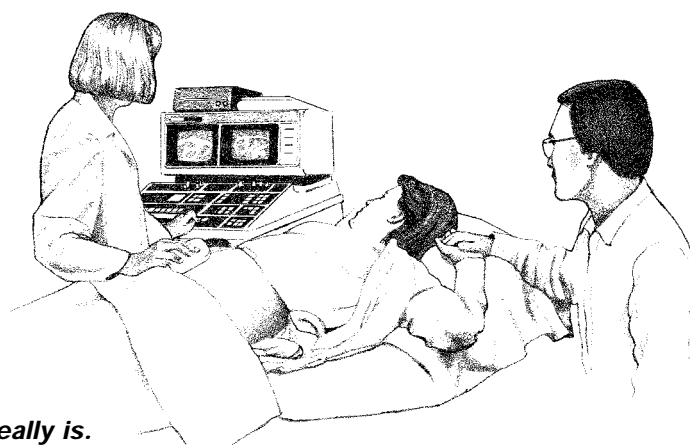
A woman may refuse any of these follow-up services at any time.

Genetic counseling:

A genetic counselor or doctor will discuss your blood test result and what it could mean. Your family's health history will be reviewed. Counseling will give you information to help you make decisions about the follow-up tests. Be sure to talk with the counselor or doctor about any questions or concerns you may have.

Ultrasound:

This test is also called a sonogram. Sound waves are used to make a picture of the fetus. This picture is seen on a special TV screen.



- ***Ultrasound shows how old the fetus really is.***

If the fetus is younger than was originally thought, the Expanded AFP blood test result will be recalculated. The new result may be “screen negative” for a fetus of that age. In this case, no further follow-up tests are offered by the Program.

Ultrasound may show that the blood test was done “too early” (before the 15th week of pregnancy). If the test was “too early”, you will be offered another blood test between 15 and 20 weeks.

- ***Ultrasound may show whether there is a visible abnormality in the fetus or the uterus.***

Amniocentesis is offered. . . .

- ***if ultrasound does not explain the “screen positive” blood test result,***
or
- ***if ultrasound finds a problem which needs clarification.***

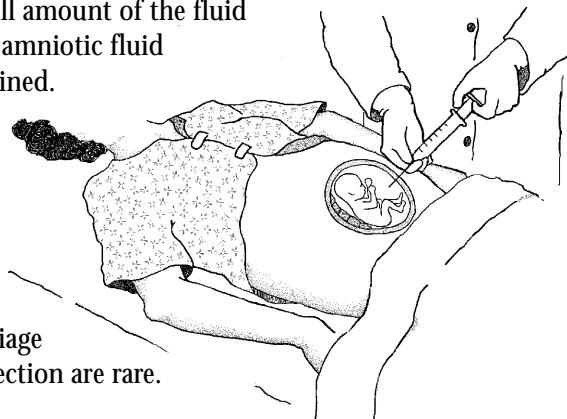
Amniocentesis:

This test involves removing a small amount of the amniotic fluid which surrounds the fetus. First, an ultrasound picture locates the fetus and the fluid. Then a thin needle is used to remove a small amount of the fluid from the uterus. This procedure sometimes causes brief discomfort. The amniotic fluid contains fetal cells. The chromosomes in these cells are counted and examined.

Amniocentesis detects almost all the birth defects caused by too many or too few chromosomes in the fetal cells. Down syndrome is an example of a birth defect caused by too many chromosomes.

The results of amniocentesis are usually ready in two weeks.

Amniocentesis is considered a safe procedure when performed by medical experts at a State-approved Prenatal Diagnosis Center. The risk of miscarriage following amniocentesis is less than 1%. Problems such as bleeding or infection are rare.



**Sometimes not all of the follow-up tests are needed.
Genetic counseling will explain which tests will be useful.**

**Most amniocentesis results are normal.
Occasionally, however, a birth defect such as Down syndrome is diagnosed.**

**Here are some facts about
Down syndrome:**

Down syndrome is a common cause of mental retardation. It is usually caused by an extra chromosome #21 (trisomy 21). Down syndrome occurs in about 1 out of 700 births.

Most people born with Down syndrome are moderately retarded; a few are mildly or severely retarded. Heart defects are common. These heart defects can usually be treated with surgery and medication. Other serious health problems often exist with Down syndrome. Medical treatment can help some of these problems.

Special programs are available throughout California to help children and adults with Down syndrome to achieve their full potential.

**If the fetus does have
Down syndrome, will the
follow-up tests detect it?**

Amniocentesis detects almost 100% of the cases of Down syndrome and other chromosome abnormalities.

What if the follow-up tests show that the fetus has a birth defect?

If a birth defect is found, a doctor or genetic counselor will give the woman or couple information about the defect and how it may affect the fetus. Available treatments and options for continuing or ending the pregnancy will be discussed. If the pregnancy is continued, delivery should take place at a major medical center in order to give the baby the best care.

The Expanded AFP Screening Program does not pay for any other medical services after the follow-up tests. Referrals for special support services are available.

Please remember:

Most women who have had a “screen positive” test result will have normal healthy babies. However, in those pregnancies with a serious birth defect, early detection allows parents to explore their options and make early decisions.

The goal of the Department is to provide high quality, low cost services to all Californians. If you have questions, comments or suggestions about services received through this program please let us know.

Write to:

george c. cunningham, md
the cal ifornia depart ment of heal th services
genetic disease branch
850 marina bay par kway, f175
richmond, ca 94804

